

OC5 Jamrozik Communicating results

[00:00:07.53] Hello, everyone. I'm Zeb Jamrozik, based at the Ethox Centre at the University of Oxford. And I'm going to talk to you today about the ethics of communicating results of HIV phylogenetics analysis. When it comes to how we use a technology like phylogenetics, it's a question of an appropriate balance between potential benefits and potential harms or risks. The potential benefits of genetics are significant. And these apply to HIV, but also to other potential pathogens. It can improve our knowledge of transmission patterns to a very great degree compared to standard analyses.

[00:00:47.80] And it can improve our evaluations of the effectiveness or cost effectiveness of intervention policies, and that can help us change the way we set priorities for public health intervention at a high level. But it can also influence the design of more focused public health programmes, looking at groups or in some cases, individuals, who are more likely to be the sources of transmission of HIV. And another benefit is that in some cases it can reduce stigma, although in other cases, of course, people worry about increasing stigma.

[00:01:21.25] It's not just phylogenetics, of course, where it's ethically important how we communicate results. The map on the right here is a map of the prevalence of people living with HIV in Africa. It doesn't include any phylogenetic analyses. It gives us important information about some areas where there happen to be more people living with HIV, but these kinds of data, even without phylogenetic data, need to be communicated carefully. Because for example, if you live in a place that's identified as an HIV hotspot or transmission hotspot in the case of phylogenetics, that can be a stigmatising label, for example,

[00:01:57.29] But in addition to those benefits, phylogenetic analysis, especially molecular cluster responses, so the use of phylogenetic data to identify and change the responses to clusters of transmission in the public health context, has raised some ethical concerns about different types of risks and ethical considerations. In particular, there's been a significant use of this approach in so-called concentrated epidemics in North America, where transmission is often concentrated among certain so-called key or sub populations such as men who have sex with men or people who inject drugs.

[00:02:37.41] And these analyses often include a high degree of linkage, linking different types of data and HIV genetic data, epidemiological, geographic data, and so on. This can significantly increase the identifiability of individuals and the potential for researchers or public health agencies to have knowledge about the direction of HIV transmission, so who infected whom, and so this involves potential stigma for people and communities who are subject to this surveillance.

[00:03:09.42] And this leads to worries that their privacy might be infringed, that in some cases their liberty might be infringed because one of the goals of this is linking people to HIV care. And that provides them with a benefit, but also people might not feel so free to make a decision about their HIV treatment if they're being identified through these kinds of surveillance means. It also leads to worries about fairness. One aspect of fairness is that if we burden people who are already marginalised or burdened in society, and we make them worse off, that increases unfairness of a certain kind in society. And so we have to be careful how we balance the benefits and burdens of our interventions.

[00:03:49.70] But of course this kind of molecular surveillance can also increase benefits for marginalised groups. So there is a question of balancing there as well. But it also has the potential to undermine trust in public health if people feel that they're constantly under surveillance with this highly identifiable technology for mapping the spread of infection. They might not trust public health agencies, they might be less inclined to seek HIV testing, and that could undermine the benefits of these kinds of programmes.

[00:04:28.05] As an example of communicating results, I'm going to talk through a few studies. This study is a report of an analysis of a public health database in Canada that has around 9,000 HIV genomes on file and gets a few new genomes per day. And potentially they can update their phylogenetic analysis on a very regular basis. It links the HIV phylogenetic data to gender, birth year, post code, so a rough idea of where people live, and their age. It links them to risk factors such as use of intravenous drugs and some questions about sexual orientation. And phylogenetic analyses are conducted on a regular basis with monthly feedback to public health agencies.

[00:05:12.84] One way of presenting the phylogenetic information is to present this kind of phylogeny on the picture here, which situates the clusters of transmission in this population in a larger database of HIV sequences. And even that we have to be careful not to have too detailed labelling within these clusters, as people within those clusters might potentially be able to identify themselves and therefore be able to identify each other, just as an example. But this way of presenting the data isn't particularly identifiable. It can be done without a lot of risks.

[00:05:48.73] Another way of other ways of presenting the data that they produce as a result of these analyses are maps of transmission networks, such as the one on the left here, which shows transmission between individuals and clusters of transmission. It also shows the amount of viral load, the amount of drug resistance, all of which might be highly private information about people, but the people within those networks would be very difficult to identify based on this. Because it's linked to geographic information,

[00:06:25.78] It's also possible to present something like the map on the right, which shows the kind of intensity of recent transmission within geographic areas. And this might lead to worries about people living in areas that are identified as high-transmission areas. But one good thing about what's presented here is that it's quite vague. It's not presented with a very highly detailed localization of where exactly people live. It's a larger picture of larger areas in the community.

[00:06:57.79] Another example of recent analysis was this study of HIV transmission networks, in part among transgender women living in Los Angeles. And this was on a public health database that included a range of information, including about sex, gender, sexual orientation, and some other risk factors. And it was one of the first analyses to show that, for example, transgender women were over represented in clusters of HIV transmission. And so this has important implications for the benefits of linking transgender women, and in particular their contacts who might infect them or vice versa, to HIV diagnosis, screening, and treatment, and also pre-exposure treatment to prevent people getting infected.

[00:07:47.74] So there's potential to increase benefits for this group. On the other hand, some HIV activists were worried about the identification of transgender people here. And one of the issues they had was that transgender women were pictured as the Centre of transmission

clusters. And if you look at this large figure from the study, you can see there's a range of different patterns presented. You can find some where transgender women appear to be at the Centre of transmission, but actually the figure is agnostic about transmission directions. But nevertheless, it shows how people can respond to the way data are presented.

[00:08:27.75] Figures are a powerful way of presenting information. They are much easier to interpret, or it can be easy to interpret and share rather than large blocks of text. But people can worry about the implications or the inferences people might draw from the way the data are depicted. And here's one other example where studies actually explicitly could be used to decrease stigma. In that first map of Africa I showed you, you could see a high prevalence of HIV around Lake Victoria region. And it was known for a long time that there was a high prevalence of HIV in fishing villages around the lake. And so some people were concerned that, for example, HIV might spread from those fishing villages to the wider community, which could be a highly stigmatising concern or set of rumours about those communities.

[00:09:23.66] But phylogenetic analyses actually showed that there was more transmission into those communities rather than out of, suggesting that the high-prevalence communities were not posing a very large risk to wider society, and so this has the potential to destigmatize those communities, at least if we can get these kind of academic world data to real people and public health agencies on the ground.

[00:09:48.04] So in summary, phylogenetic analyses can give us very precise maps of HIV transmission networks, especially when they are linked to other types of data. Researchers and public health agencies, therefore, have a duty to communicate these data especially carefully. They're very powerful in terms of their ability to produce benefits. But other ethical aspects of the way data are communicated include the potential identifiability of individuals and privacy infringements, how we describe people in communities, both in the text and the images presented in publications, and also issues of fairness or justice. One implication of fairness is we want to increase the benefits for marginalised groups and we don't want to stigmatise them further. So with that I'll say thanks very much and I look forward to hearing your thoughts.